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Impacting Audiences: Responses to Oral Histories of Persons with Schizophrenia

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Abstract

The current article focuses on the impact for listeners of oral histories of persons with schizophrenia, presented to 241 audience members. Post-presentation feedback was obtained. Findings from a mixed-methods design combining chi-square analyses with qualitative presentation of emerging themes present evidence to support new learning, emotional impact, and motivational inspiration in listeners.

Keywords

Schizophrenia, Oral History, Stigma, Impact

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Impacting Audiences: Responses to Oral Histories of Persons with Schizophrenia

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The current article focuses on the impact for listeners of oral histories of persons with schizophrenia, presented to 241 audience members. Post-presentation feedback was obtained. Findings from a mixed-methods design combining chi-square analyses with qualitative presentation of emerging themes present evidence to support new learning, emotional impact, and motivational inspiration in listeners. Keywords: Schizophrenia, Oral History, Stigma, Impact

Many Americans have a distorted understanding of persons with severe mental illness. Influenced by inaccurate and stereotypical media reports, persons with severe mental illness are seen as confused, unpredictable and often violent (NAMI, 2008). While most persons with severe mental illness do not fit that stereotype, they are still treated with fear and rejection because others believe the stereotype. Attempts to educate the public in traditional ways (i.e., sharing of factual information to increase intellectual understanding of the mental disorder) have not shown much progress (Pescosolido et al., 2010), hence the call for more effective methods of challenging stereotypes of persons with severe mental illness. This is where humanizing methods are beginning to show some impact (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012). In contrast to the intellectual approach of traditional methods, humanizing methods involve personalizing the information to include some form of contact with a mentally ill individual, challenging myths and/or raising awareness of unfair prejudices. With *The Schizophrenia Oral History Project (TSOHP)*, we are attempting to challenge inaccurate stereotypes of persons with schizophrenia or schizoaffective disorder (a diagnosis involving the combination of schizophrenia and a major mood disorder – major depression or bipolar disorder) through the humanizing vehicle of oral history. *TSOHP* records and archives life stories of persons with schizophrenia and provides public talks to introduce professional and lay audiences to the people behind the diagnosis by listening to and discussing audio-recorded excerpts from individuals' life stories of living with mental illness. In doing so, the project aims to reach listeners on both intellectual and human levels. The current study provides evidence to suggest that *TSOHP* is changing audience perceptions and emotional reactions to persons with schizophrenia.

TSOHP is not an archive of illness narratives, but rather of the life stories of those with schizophrenia. This distinction is important because the aim is not to educate the public as to the illness itself, but to introduce others to the person behind the illness. Often when people are diagnosed with schizophrenia, they become reduced (in the eyes of others) to their diagnosis. When people become merely diagnoses, there is the danger that they will be seen as not quite human, nor as someone with whom others are able to relate. Stereotypes and stigma can arise from this detachment. However, when people are viewed as similar to ourselves – human

beings – there is greater empathy and human connection. And when we have empathy and feel connected, stereotyping is decreased.

Description of Schizophrenia

Schizophrenia is perhaps the most severe of the chronic mental illnesses. It is described in the *Diagnostic and Statistical Manual of Mental Disorders 5* (American Psychiatric Association, 2013) as a psychotic disorder in which an individual has periods of time losing contact with reality and experiences both positive symptoms (positive referring to a behavioral excess - something atypical occurs behaviorally) and negative symptoms (negative referring to a behavioral deficit - behavior that is typical and desirable disappears). Positive symptoms most commonly include delusions and hallucinations. Delusions are ideas that someone strongly believes that have no basis in fact, and hallucinations are perceptual experiences that are not caused by external sensory stimulation, most likely manifesting as hearing voices speaking as if outside or inside the head. On the other hand, negative symptoms commonly include social withdrawal, lack of voluntary activity, reduction in spontaneous speech and restricted range of affect.

Although there is much we don't know about the cause of schizophrenia, the evidence at present is consistent with a diathesis-stress model, that certain individuals are born with a biological predisposition to develop schizophrenia (the diathesis) and that various demands in the external environment (the stress) increase the expression of the disorder and the severity of its course in these individuals. Schizophrenia is a chronic and lifelong mental illness; there is no known cure, and treatment typically focuses on symptom management. However, despite its chronic nature, people who have schizophrenia are not always out of contact with reality. The trajectory of the illness is such that it creates periods of time in which contact with reality is disrupted, but there are also periods during which the individual is lucid and able to make grounded judgments. These latter periods of wellness are further increased for individuals who are compliant with their treatment, which primarily involves the use of antipsychotic medication. The nature and course of schizophrenia are misunderstood by most of society in that the common inaccurate characterization is of individuals who are tragically and irreversibly lost to symptoms that provide them with no ability to connect with the real world.

Misunderstanding and Stigma

People with schizophrenia are commonly misunderstood, stigmatized, and discounted, and they have little or no opportunity to have their voices heard (Link, Cullen, Frank, & Wozniak, 1987). The typical media portrayal of persons with severe mental illness is of individuals who are chronically confused, disconnected from reality and other people, and oftentimes violent. Although it is true that severe mental illness does cause confusion and disconnection *at times*, individuals who suffer from severe mental illness can also have periods of time in which they are clear and not only capable of connecting with others, but able to do so on a deep level. Furthermore, although some persons with severe mental illness can become violent, that is the exception rather than the rule. In fact, persons with severe mental illness are 14 times more likely to be the victims of violence than the perpetrators (Brekke, Prindle, Bae, & Long, 2001), and in the relatively few instances when violence does occur, it is mediated by substance abuse and likely to be directed toward themselves (Martone et al., 2013; NAMI, 2008).

Nevertheless, according to the National Alliance on Mental Illness, 60 percent of the American population believe that those with schizophrenia are likely to be dangerously violent (NAMI, 2008), and the accompanying stigmatization of those with schizophrenia is not a new

phenomenon. Although there has been an increase in the understanding of the causes of mental illness, rates of stigmatization towards the mentally ill have nonetheless also increased from 1950 to 1996 (Phelan, Link, Stueve, & Pescosolido, 2000). While these researchers did see a trend toward acceptance of many forms of mental illness, as well as a greater tendency to connect with mental illness as something that could happen to “me”, they also found that this acceptance did not extend to persons with psychotic disorders such as schizophrenia. As a society, we still misperceive persons with psychotic disorders as unpredictable and violent, and societal perceptions of violence among individuals with psychotic disorders has increased by 2 ½ times over those 46 years. The misperception of individuals as violent is an important component of stigma against persons with mental illness (Link et al., 1987).

Beginning with the U.S. Surgeon General’s first ever report on mental illness in 1999, it has been suggested that a more scientific understanding of mental illness may lead to decreasing stigma, particularly if that understanding points to a biological causation (U.S. Department of Health and Human Services, 1999). If a human problem is framed as biologically induced, individuals are less likely to be seen as personally responsible, and are thus believed to have “real” problems. As a result, we tend to have greater empathy for their struggle. But for persons with schizophrenia, increased biological explanation has not resulted in reduction of stigma. Pescosolido et al. (2010) found that the rate of stigma since 1996 has remained constant despite recent advances in a neuroscientific understanding of schizophrenia. Undeterred by greater scientific understanding, a majority of the public still indicated that they were unwilling to work closely with someone with schizophrenia (62%), were unwilling to socialize with someone with schizophrenia (52%), and were unwilling to allow someone with schizophrenia to marry into their families (69%; Pescosolido et al., 2010). Such evidence makes it clear that a greater intellectual understanding of severe mental illness is not effective in reducing stigma, at least not for persons with schizophrenia. Thus, researchers have turned to examining the effects of humanizing methods.

Three main humanizing interventions discussed in the literature in regard to stigma reduction are: contact, education, and protest. Contact features people with mental health challenges in either video (watching a person with a mental illness being interviewed about their experience on video) or in-vivo (interacting with the person directly) presentations (Corrigan, Larson, Sells, Niessen, & Watson, 2007; Rusch, Kanter, Angelone, & Ridley, 2008). Education increases knowledge about mental health by replacing myths with facts (Watson et al., 2004). And, protest raises awareness about unfair prejudices (Corrigan, Edwards, Green, Diwan, & Penn, 2001). Contact and educational strategies have been shown to be more effective than protest because protest can trigger a rebound effect that tends to worsen attitudes toward persons with mental illness (Corrigan & Penn, 1999). When contact and educational strategies are compared, however, it appears that contact strategies seem to lead to stronger outcomes than educational methods (Corrigan et al., 2012), making contact the superior vehicle for attitudinal and behavioral change in the population.

The Schizophrenia Oral History Project (TSOHP) is a powerful example of the use of contact to challenge stigma. It is our belief that as listeners hear the words (in their own voices) of individuals in this project who demonstrate awareness and concern for others, it will then be difficult for them to continue to believe the stereotypes of violence and disconnection.

The Schizophrenia Oral History Project

Author Context

The first two authors (TM and LC) initiated *The Schizophrenia Oral History Project (TSOHP)* in the spring of 2011 in the hope of providing a forum for individuals with

schizophrenia who would otherwise not be able to speak or write publicly about their lives. Both are psychologists on faculty at Mount St. Joseph University who had professional experience working with individuals with severe mental illness prior to working in academia; however, each was focused on other areas of inquiry before *TSOHP*. Dr. McDonough was investigating various issues related to interpersonal violence (McDonough, 2010) and human sexuality (Wester, McDonough, White, Vogel, & Taylor, 2010), while Dr. Crane's background is with individuals with mental disabilities, having authored a book on developmental disabilities (Crane, 2002). In addition, Dr. Crane's son, Doug, struggled with schizophrenia and took his life several days before his 25th birthday, so she has both an academic and a personal understanding of societal treatment of persons with severe mental illness. Approximately 15 years following her son's suicide, they started *TSOHP* with the hope of increasing empathy and understanding toward persons with schizophrenia by recording and publicly sharing their life stories.

The second two authors (KP and SV) were undergraduate psychology students at the beginning of this project. Both were upper level students striving to gain admission into graduate school and as well as broaden their research skills with *TSOHP*. The curriculum at Mount St. Joseph University for a psychology degree involves a 3 course research sequence that focuses on quantitative methods. The students wanted to work on the project to both increase their understanding of persons with schizophrenia as well as to gain experience in implementing qualitative methods of analysis. They presented initial findings from this analysis in poster form at the Rocky Mountain Psychological Association meeting in 2014 (Vice, Phelps, McDonough, & Crane, 2014).

Description of the Project

TSOHP is an ongoing oral history project that has been approved by the Mount St. Joseph University Institutional Review Board (IRB). Although oral history projects in general have been determined as not needing IRB review, because we included analyses of audience responses to excerpts from public presentations about this oral history project, we sought and received IRB approval prior to data collection. Participants in the current project were contacted via in-person talks or flyers distributed at community mental health centers asking adults with schizophrenia or schizoaffective disorder to contact the interviewers if they wanted to record their life stories. Individuals were then assessed for the ability to provide informed consent to participate in the project. Narrators could still be experiencing symptoms, but needed to be able to understand the procedure of the project and the uses made of their stories. After informed consent was received, individuals were interviewed in a location convenient for them, often either in their home or in a quiet space in a community mental health center, where their stories were audio recorded and photographs (optionally) were taken.

Although many individuals did talk about their illness in the recordings, often they did not, and stories tended to focus more broadly on their lives in general. Narrators were encouraged to talk for as long as they liked to tell their stories; however, most recordings ran approximately 45 minutes to an hour. The interviews were primarily open-ended, with narrators being asked only a few standard questions including: "Can you tell us about your life? We'd like to know about you." "What is a typical day like for you?" "What would you most like people to know about you and your life?" and "What has this experience of talking today been like for you?" Additionally, it's important to note that narrators could choose whether to respond to a question or not, further reflecting the authenticity of their stories.

The goals of the project include giving our narrators a voice—an experience that appears to be empowering for them—and to share their life stories publicly, in order to reduce stigma against those with mental illness. To date, fifty-one narrators with a diagnosis of

schizophrenia or schizoaffective disorder have recorded their stories for *TSOHP*, and we have given over 50 public presentations of our narrators' stories (through audio excerpts and photographs) to mental health providers, mental health advocacy groups, and undergraduate and graduate college classes taught by one of the authors or colleagues in the local area. Additionally, our website (www.schizophreniaorahistories.com) offers information about *TSOHP*, provides individual pages for each of the narrators (featuring audio excerpts), and offers contact information for anyone with schizophrenia who might want to participate.

During the presentations, audience members listened to excerpts from the oral histories of a small group of persons with schizophrenia (3 or 4 narrators) while presenters provided commentary on themes present in the excerpts such as meaning/purpose, stigma and coping. Important elements illustrated by the excerpts, included alternative but creative and effective methods of coping with schizophrenia, narrator insights into their illness (a common new insight for mental health providers, as will be discussed later in this article), as well as simple but pertinent messages from narrators to the public: "I'm just a human being with a problem," (Alice Fischer) and "Take time to consider what would you be? What would you feel like? How would you cope if you were in the same situation? How would you do it?" (Paul).

TSOHP offers an opportunity to promote empathy and understanding for those with schizophrenia among the public. Because these presentations allow listeners to come into more "direct" and personal contact with those who have the disorder than is possible through merely reading about the disorder itself or written personal accounts of living with it, listeners may be more likely to be impacted in ways that change their thinking, affect them emotionally, and produce the motivation to take some action to change the social climate for sufferers. This study analyzed audience feedback from *TSOHP* presentations to determine to what extent listeners reported educational, emotional or motivational responses as a result of their exposure to narrators' stories.

Method

Participants: Narrators

As stated above, *TSOHP* is an ongoing project in which persons with schizophrenia or schizoaffective disorder are interviewed by one of the authors about their life stories and audio recorded for preservation. Once completed, the audio file is transcribed and then an individual web page is created for each narrator's story on the *TSOHP* website. Although there are a number of individual life stories of persons with schizophrenia available in the public domain, to our knowledge this is the only formal collection of life stories of persons living with schizophrenia. The collection currently includes stories from 51 narrators, ranging in age from 26 to 67, from various locations in the United States, the majority of whom reside in and around Cincinnati, OH. There are 28 females and 23 males. With respect to race/ethnicity, 37 are Caucasian, and the rest are African-American, with 2 Hispanic individuals, 1 Vietnamese individual, and 1 individual who identified himself as "Mixed Race."

Presentation Content

We have recorded 51 narrator stories to date; however, due to time limitations and the level of depth required to create a humanizing presentation (i.e., In the span of a 60-minute talk, it wouldn't be effective to merely present one-line excerpts from each of our narrators' stories), we limited the material to include excerpts from a subsample of narrators (Alice Fischer, Paul, Derrick Little, Amber, and John - see the *TSOHP* website for their stories). One version of the public talks (our standard presentation) included stories provided by Alice

Fischer, Paul and Derrick Little, whereas the second version (a modification of the standard presentation created specifically for a keynote talk at a university wide event) focused on stories provided by Alice Fischer, Paul, Amber and John. However, because there was a great deal of overlap in the themes discussed in both presentations, we did not see the content different enough to separate out responses from the two versions of the talks. Review of the qualitative data confirmed this, in that both versions elicited a similar number of educational, emotional and motivational responses from audience members. A very brief, 5-minute version of our talk can be found on the About page of the *TSOHP* website (<http://www.schizophreniaoralhistories.com/about>).

Participants: Audience Members

Although the participants in *TSOHP* are the narrators, in this investigation, our narrators provided the material for the public talks, and audience members at these public talks are the participants providing the data for analysis. Audience members ($N = 241$) were adults of varying educational backgrounds and professions (e.g., case managers, social workers, psychologists, psychiatric nurses, undergraduate and graduate students). Audience sizes ranged from 10 to 115, depending on the forum (large university sponsored event, graduate school class, undergraduate social work club, hospital unit, clinician continuing education presentation, etc.).

Procedure

We presented stories from *TSOHP* at various universities, mental health agencies and general community gathering areas in the Greater Cincinnati area from 2011 to 2013. Following the presentations, we asked audience members to complete attendee feedback forms (see Appendix) that solicited their understanding and reactions through open-ended questions that were coded for type of response (see Results section). They were asked in what role, if any, they worked with individuals with schizophrenia, their general reactions to the presentation, and insights gained from the presentation. They were also asked additional questions that were not included in the current analysis but can be seen in the Appendix.

Results

Quantitative Analyses

Sample Characteristics

Audience members were categorized into one of four groups: (a) trained mental health worker who has had contact with people with schizophrenia, (b) trained mental health worker without such contact, (c) not a trained mental health worker but has had contact with people with schizophrenia, and (d) not a trained mental health worker and has not had contact with people with schizophrenia. Audience members were coded as being trained mental health workers if they reported having professional mental health training or were employed in a mental health related occupation. Audience members were coded as having contact if they simply knew someone with schizophrenia – the contact did not have to be ongoing or result from a close relationship. Overall, 241 audience members provided responses for the current analyses. Of these, 63.5% had no mental health training, and 69.7% had no prior contact with someone experiencing schizophrenia. Further, 54.8% had both no mental health training and

no prior contact with someone with schizophrenia. Thus, the majority were relatively inexperienced with and uneducated about persons with schizophrenia.

Determination of Coding Categories

Audience responses were coded for educational, emotional, and motivational content. An educational response indicated learning something new about the illness (e.g., “I learned more about a disorder I am unfamiliar with and learned about the stereotypes.”) or about the people who struggle with it (e.g., “These folks are just as normal as me but with an added challenge.”). Although the feedback form explicitly asked if the audience member gained any insights, a review of answers provided indicated that not all responses to this question were educational. In order to be coded as educational, the respondent needed to report that they did, in fact, learn something specific. Broad general statements (e.g., “This changes the way I think about stereotypes.”) were not considered educational.

Next, a response was coded as emotional if it indicated any internal feelings experienced by the participant, such that they felt moved or touched in some way (e.g., “Made me feel so much more compassion for others and their personal struggles”). A distinction was made between uses of emotionally laden words to describe the presentation versus reporting an internal emotional state. For example, commenting that the presentation was amazing (“What an amazing project!”) was not coded as emotional, whereas stating feeling amazed at something a narrator was able to accomplish (“I was amazed at the courage the narrators have to tell their story.”) was coded as emotional.

Finally, a motivational response displayed a call to action or indicated a behavior change in the participant specifically, rather than in society as a whole. For example, “Reminds me to be more compassionate,” would not receive a motivational code. To fit in the motivational category, audience members needed to voice personal intent to change behavior (e.g., “Hearing stories from the narrators, it made me realize to treat everyone with the utmost amount of respect.”). General statements about what society or people as a group should do (e.g. “We shouldn’t judge others.”) were not coded as motivational.

Inter-Rater Analyses

Three of the authors (TM, KP and SV) met to define the coding categories described above and then separately rated the responses for educational, emotional and motivational content. Because the students were novice raters, they were initially paired to agree upon one set of ratings while TM provided a second set of ratings. Inter-rater reliability analyses were then conducted for agreement between the two sets of ratings. Results of these analyses were initially less than .80 (the typical standard for minimum agreement) for the motivational and educational categories. Thus, revisions were made to the coding criteria for these two categories, and responses were re-coded. Final coder agreement for emotional, motivational, and educational response categories then reached .86, .82, and .85, respectively.

Descriptive Analysis of Response Categories

The percentage of responses for each category in the overall sample showed that 69.7% indicated an educational response, 51.0% had an emotional reaction, and 22.4% exhibited a motivational reaction. To further understand participant responses, the overall sample was first divided into two groups: (1) participants with prior mental health training and (2) participants without prior mental health training. Of those who did have mental health training, 62.5% reported an educational response, 46.6% had an emotional reaction, and 19.3% were motivated

to act on something heard in the presentation. Of those who did not have mental health training, 73.9% indicated an educational response, 53.6% had an emotional reaction, and 24.2% had a motivational reaction. Based on raw percentages, it appears that more of those without mental health training were impacted than those with mental health training; however, it is of note that almost two-thirds of those with mental health training learned something, suggesting that there is an educational component to *TSOHP* oral history presentations that allows even experienced mental health professionals to achieve some new understanding of those with severe mental illness.

The overall sample was next divided into: (1) participants who had some prior contact with someone with schizophrenia and (2) participants who had no prior contact with someone with schizophrenia. The percentages for whether audience members had prior contact with persons with schizophrenia showed that of those who did have prior contact, 58.9% reported an educational response, 52.1% had an emotional reaction, and 17.8% reported a motivational reaction. Of those who did not have prior contact with persons with schizophrenia, 74.4% learned something new, 50.6% had an emotional reaction, and 24.4% were motivated to some form of change. It appears that at least for educational responses, those without prior contact were more likely to report an impact, but more than half of those with prior contact also reported having learned something specific.

Chi-Square Analysis

Chi-square analyses for all three types of responses were conducted for both prior training and prior contact variables. A significant relationship was found between contact and educational responses in the overall sample, $\chi^2(1, \eta = 241) = 5.79, p = .02$, such that learning something about schizophrenia from oral histories significantly related to whether attendees had prior contact with someone with schizophrenia. Those with no prior contact with persons with schizophrenia were more likely than those who had prior contact to indicate learning something new about schizophrenia. This finding is consistent with the *TSOHP* goal of educating the general population about mental illness.

Qualitative Thematic Analyses

After audience responses were grouped into the 3 coding categories (educational, emotional, and motivational), responses that were coded in any of those 3 categories were listed in an overall database. To obtain a richer understanding of the audience feedback, we identified common themes that emerged within the coding categories. The themes were not predetermined, but rather were identified using an inductive thematic approach (Braun & Clarke, 2006) that was data, not theory, driven.

Educational Responses

Both novice listeners and mental health professionals reported learning something from *TSOHP* presentations; however, as expected, the level of sophistication in insight did vary. For those who were initially unfamiliar with schizophrenia and had not had prior contact with individuals with schizophrenia, many reported acquiring basic knowledge that was new to them (“Did not know what schizophrenia is. Very informational.”), as well as learning of the difficulty of living with a chronic mental illness (“It really opens my eyes to what it’s like living with schizophrenia. These people are fighting against schizophrenia every day, every hour. It made me realize just how difficult living with schizophrenia really is.”). Several also commented on the effectiveness of the vehicle – oral history – to educate people about mental

illness (“It was much more helpful than reading about the disease in a book.”). Other responses included awareness of the humanity of people with schizophrenia (“I gained insight on who these people are as people and not just a disorder.”), narrator desire to live a normal life (“People dealing with this disease are just trying to live a normal life and it's so hard.”), and a move away from seeing people with schizophrenia as “crazy” (“I'm glad to have my perceptions of schizophrenia formed by this presentation, specifically that these people are ill, not crazy or evil, and that they have huge obstacles to overcome.”).

In addition to reports of new basic knowledge, many novice audience members indicated learning something that refutes the various stereotypes of schizophrenia. Those stereotypes included that persons with mental illness are not intelligent (confusing psychological state with intellectual abilities), are unaware of what is said about them, and are violent. In contrast, audience members reported new understandings that persons with schizophrenia are capable of being smart (“I realized those with schizophrenia have the ability to internalize and have high intellect.”), are aware of what others say about them (“I found it revealing that these narrators were so aware of others' reactions to them.”), are not usually violent (“Schizophrenia isn't at all what I originally thought. They aren't violent, dark people.”), and that narrators themselves are aware of the stereotypes (“They understand the stereotypes and they want to prove that they are wrong.”). These responses indicate that *TSOHP* presentations did counteract stereotypical thinking for at least some audience members.

Among those with experience in the mental health field, foundational knowledge was less likely to be reported. Although this is consistent with the prior knowledge expected of those in the mental health field, it was not the case that our presentations lacked educational value for these experienced audience members. These listeners frequently learned that individuals with schizophrenia can have insight into their illness and that they can have some awareness of the fact that they are ill even during acute periods of symptoms. This insight was most often reported in response to one of *TSOHP*'s narrator's descriptions of how he copes with hallucinations. The narrator, Paul, stated, “I'll see things. I'll hear things that I don't respond or react to. I've learned that much... You just quietly sit there, turn everything off, and just sit there and just let it happen, until it runs its course.” It is clear from this excerpt that Paul is aware that at times he hears or sees things that are not externally present, and when that happens, he sits quietly until the symptoms pass. Audience responses to Paul's excerpt (“These narrators have insight into their own ‘insight deficiencies.’ This is amazing.” “I had a misperception that individuals struggling with mental illness (schizophrenia) do not have insight when in fact they do.”) indicate surprise at Paul's insight into his condition and his ability to manage his symptoms. Therefore, our results show that some mental health workers have assumed the stereotypical position that insight is unavailable to those with schizophrenia and have abandoned that stereotype in response to Paul's description. Paul's excerpt convinced them that insight is, in fact, possible, even in the throes of active symptomatology. As one audience member so eloquently stated, “It was surprising to see how much insight each narrator had. As a mental health worker, I would always have assumed I would be less stereotypical of someone with schizophrenia, but the fact that these stories surprise me tells me I need to do more work to see the person minus the schizophrenia.”

Emotional Responses

In addition to educational responses, responses were coded for emotional content – something we believe indicates a deeper level of impact than merely gaining new knowledge, as important as this knowledge may be. While achieving greater understanding of what someone is going through can be helpful, feeling for them may mean the individual has made a deeper connection. Making a deeper connection may be more difficult than a surface

connection, so fewer people would be likely to report an emotional response than an educational one. That dynamic is consistent with our results that a smaller percentage of audience members reported an emotional response (51.0%) than an educational response (69.7%).

Audience members reported a range of emotional reactions. Although some were positive (“I found it heartwarming.”), more were negative (“I feel horrible for not understanding more. I am also ashamed to admit that I was unaware of how highly functioning a person with this illness is.”), and a number of listeners reported feeling both positive and negative emotions at the same time (“They’re heartbreaking and uplifting - these narrators have such resilience. Hearing the narrators’ stories straight from the source was very, very powerful.”). Whereas some audience members gave a general emotional response of feeling moved (“Very moving. Wow!”), it was more common for listeners to identify specific emotions such as feeling surprised or shocked (“I find it shocking because it disproves every preconception.”), sad (“Yes, it saddens me to hear these actual stories and the responses they receive from our society.”), impressed (“Very impressed with the resilience of these folks and their many insights and strengths.”) and amazed (“I was amazed at the courage the narrators have to tell their story.”). The overarching theme that emerged across the emotional responses was increased empathy (“My general reaction is that I feel their pain.”) and compassion (“Made me feel so much more compassion for others and their personal struggles.”).

Motivational Responses

It is clear that audience members learned something and felt something in response to the oral history presentations, but to be moved to the point of wanting to do something, to change one’s own behavior, is reflective of an even deeper impact than both educational and emotional reactions. This further depth of impact might be expected to be less common than emotionality elicited and is, again, consistent with the finding that the smallest percentage of audience members indicated some kind of motivational response (22.4%).

The most prominent theme that emerged within the motivational responses was the recognition that personal behavior with respect to how one treats others needs to change. Although some indicated a general need to treat people better (“Hearing stories from the narrators, it made me realize to treat everyone with the utmost amount of respect.”) or that they were inspired (“I was also inspired to see their positive outlook.”), others were more focused on what they wanted to do. A number of audience members commented on specific behaviors they intended to change such as not judging others (“Their stories are inspiring. It makes me think twice about judging and viewing others.”), listening better (“I am reminded to stop and listen.”), not taking life for granted (“I also know not to take anything for granted now.”), learning even more about mental illness (“I am not educated enough about schizophrenia to allow myself to form an opinion. Seeing these stories, they have inspired me to get more educated about this.”), and needing to help others (“Being aware of these difficulties gives me a greater drive to help others.”). Some even indicated rather lofty goals such as challenging stereotypes (“Schizophrenics are humans. This knowledge will help me to break and stop negative stereotypes about mental illness.”) or making a difference in the world (“As a citizen of the world, it is my duty to take care of those who don’t have that capability. As a person in a career field, these people and their stories make me want to make a difference. To help change how the world sees people with disorders and to have the general public become aware and no longer fear the unknown.”). And, although the majority of the motivational responses were about interacting with others differently, a small group of listeners were motivated towards self-care and acceptance (“Makes me feel I can cope with my own less complex issues.”).

Discussion

In the current study, over two-thirds of the audience members learned something new, one-half experienced an emotional reaction, and one-fifth indicated motivation to modify their behavior, showing that listeners report measurable change on several levels after hearing *TSOHP* narrators' stories. Evidence also showed that the impact of narrators' stories was not limited to those who had no prior understanding of or exposure to schizophrenia. Mental health providers -- sometimes professionals working with individuals with mental illness for many years -- also learned something of value from these oral history presentations. And further, audience members spontaneously identified the impact they believe that came exclusively from the use of oral history as the method to deliver the message ("I feel this is a very powerful way to hear the message. It is one thing to read about schizophrenia in a textbook, but it's another to hear it from someone who has schizophrenia." "Hearing the narrators' stories straight from the source was very, very powerful. It has a greater impact than statistics, reports, secondary reporting.").

Importance of an Accurate Understanding of Schizophrenia, Especially in the Current Social Climate

For the general public, information about schizophrenia comes primarily from the media. In a study of more than 11,000 news articles involving schizophrenia published between 2000 and 2010, Emory researchers found that more than 60% of the human interest stories portrayed violent acts (Vahabzadeh, Wittenauer, & Carr, 2011). Of particular concern, in spite of the fact that more persons with schizophrenia are victims rather than perpetrators of violence, only 5% of the articles reviewed reported victim events. Public perceptions of persons with schizophrenia mirror these media findings. According to the National Alliance on Mental Illness, 60% of the U.S. population continue to believe that those with schizophrenia are likely to be dangerously violent (NAMI, 2008). These mistaken views make support and acceptance for those with schizophrenia less likely, and obscure the true root causes of those violent acts that do occur.

As previously stated, the public view of those with schizophrenia is of people who are violently dangerous, incoherent, and incapable of insight (NAMI, 2008). Further, even professionals who have worked with persons who have schizophrenia often do not perceive their coping and resilience. They continue to stereotype and stigmatize as frequently as those who have had no experience, and they are unwilling to socialize with them (Nordt, Rossler, & Lauber, 2006). According to Schulze and Angermeyer (2003), patients often report especially stigmatizing experiences with those who have been assigned to treat them. Additionally, and contrary to intuitive belief, increased knowledge about mental illness actually correlates with greater stigmatization (Jorm, 2000). Our results show, however, that the "personal" encounters our audiences have through oral history presentations do change perceptions among both mental health professionals and the general public. Some respondents even spontaneously offered that their notions about violence in the population were wrong.

Need for a Humanizing Approach to Challenging Misunderstandings

Recently, more of the scientific literature has exposed myths about schizophrenia, including that it is not caused by poor parenting, that the personality characteristics and symptom expression of those affected is diverse, and that the outcome is often much better than previously thought (Lillienfeld & Arkowitz, 2010). While this knowledge has become increasingly well accepted, it has not led to a better understanding of the specific abilities and

capabilities of, nor decreased the fear toward, those with schizophrenia. Most people continue to express the belief that those with schizophrenia can be expected to be violent, show little insight, and are unaware of the reactions of others, so these intellectual reports do not appear to be changing stereotypical beliefs of the average American. As we have discussed elsewhere, the nearly exclusive focus in the schizophrenia literature on the illness itself has overlooked the human experience, the frequently occurring strengths of resilience and coping, and the importance of meaning and purpose in the lives of those with the illness (Crane & McDonough, 2014). Oral histories provide evidence of those strengths and, unlike others forms of research, provides a tool that allows the public to come into “direct” contact with those with schizophrenia and to show them that their perceptions are mistaken. *TSOHP* narrators’ stories refute these preconceptions, and impact audiences in ways that do change their beliefs and attitudes, suggesting that showing people that their beliefs are mistaken may be more effective than simply telling them that their beliefs are mistaken.

Needed Political Reforms That Are More Likely If Understanding Improves

Although individual change is important, it is not lasting unless it leads to larger societal change. As such, there are a number of needed reforms that may become more likely with increased understanding and support for those with schizophrenia. These include:

- Greater support for research that can find ways to counteract the effects of the illness and perhaps find a cure.
- Greater support for funding treatment and support measures that research currently shows are effective in reducing symptoms and enhancing quality of life.
- Less fear and hopelessness about the disorder that can make those who are affected more likely to seek treatment.
- More effective treatment that can reduce the incidence of those rare, but sometimes deadly, acts of violence that do result.

As these reforms are enacted, quality-of-life for the millions who are affected will result, positively impacting not only those with the illness but the families and others who care about those with schizophrenia as well. But these reforms will not be possible until there is a change in the societal understanding of persons with severe mental illness.

Limitations and Suggestions for Future Research

Although we have provided evidence of the impact of oral history on belief systems, no study is flawless. One limitation has to do with our recruitment procedure for our narrators. Individuals with schizophrenia are frequently exploited, so trusting new people takes time for both the individuals with the diagnosis and also with those who treat them. Thus, we have mostly been able to recruit from local agencies with whom one of the authors (TM) has a relationship. As the project has grown, we have included others from different parts of the country who have found our website; however, a more systematic recruitment procedure, though likely difficult to implement, would provide a greater range of stories to share with audiences.

A second limitation has to do with our feedback form. Looking at the pattern of coded responses to the presentations, it is not surprising that the percentage of people having a motivational response was the smallest, as it is of greater impact to feel motivated to change one’s behavior than it is to merely gain a greater intellectual understanding. In addition, it is

important to note that the reports of both emotional and motivational reactions were spontaneous responses to the question asking for general reactions; however, educational responses were specifically elicited with the question asking for insights gained. Thus, it is likely that more educational responses were obtained, in part, because they were specifically requested. When designing the feedback form, we were initially interested in collecting general feedback and evidence of educational learning. However, as commonly occurs in inductive research (Braun & Clarke, 2006), once we reviewed the data, additional themes (emotional and motivational) emerged.

A common mantra among creators of educational rubrics is “You get what you ask for” when creating assignment prompts. The same holds true for feedback forms such as the one used in the current project. Because it is likely that we would have received more emotional and motivational responses if we had specifically asked for them, this study may actually underestimate the impact of narrators’ stories on listeners. Future researchers may want to directly explore this possibility.

A final limitation has to do with generalizability. The overwhelming majority of our audience members were students or mental health professionals attending our talks for licensure or education credits – in other words, individuals who were already motivated to learn something. In order to change stereotypical beliefs on a societal level, the material needs to influence those who are open to new learning as well as those who aren’t so primed. Thus, future researchers could investigate the potential impact of oral history presentations on a broader range of members of the lay community. In addition, the current project did not include a direct comparison of audience responses to oral history versus more traditional educational formats (e.g., lectures). Future investigators could attempt a more systematic investigation of oral history methodology in comparison to more traditional methods of education to explore this dynamic further.

Summary

Schizophrenia affects approximately twenty-one million people worldwide (WHO, 2016), and the lives of those with schizophrenia are negatively impacted by misunderstandings about the illness. Evidence from the current project suggests that oral history may offer a humanizing and effective method of educating the public about groups of “others” and may provide a potent tool in ameliorating harmful stereotypical thought and action. The use of oral history to impact stereotypes has not been studied widely, yet we hope that the findings from the present study may prompt more frequent use of oral history to educate and promote change as well as more rigorous research to investigate the effects.

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Appendix

The Schizophrenia Oral History Project

Attendee Feedback Form

As you will learn through the course of our discussion today, our intent in the current project is to not only learn about Schizophrenia directly from those struggling with it, but to also be able to honor them for their willingness to share their life stories with us. Part of that honoring will involve sharing anonymous feedback from people like yourselves to hearing their life stories, so we ask that you respond to some brief questions below before leaving tonight.

In what role, if any, do you currently work with individuals with Schizophrenia?

What are your general reactions to hearing these life stories? What was it like to hear the narrators speak about themselves in this way?

What moment/comment stood out to you the most? And, why did it stand out?

Did you gain any insights by hearing our narrators' stories? If so, please explain.

And finally, if you have any thoughts, reactions, etc. that did not fall into any of the above items but you would like to share with the narrators, please write them here.

In addition to sharing your comments with the narrators, we would like to ask for your separate permission to include your comments in our research analysis and share them at future public presentations. Choosing to give permission to use your comments for research purposes is entirely voluntary and if you do not want us to include them in the research, we will still share them with our narrators. And, choosing not to participate or discontinuing participation in the research aspect of this presentation will involve no penalty or loss of benefits to which you are otherwise entitled, including any benefits you may be receiving at this facility.

May we have your permission to include your comments in our research analysis and share them anonymously at future presentations? Yes No

Thank you for your time and attention today! We hope that you have found it of value. We certainly have.

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